CPR Center for Public Representation

March 26, 2020
By Electronic Mail

Governor Charles Baker
Secretary Marylou Sudders
Lt. Gov. Karyn Polito
Attorney General Maura Healy
Senate President Karen Spilka
Speaker of the House Robert DeLeo

Dear Governor Baker and other distinguished State officials:

We write on a matter of urgency regarding non-discriminatory access to life-saving medical care for people with disabilities across the lifespan, including those with psychiatric, developmental, intellectual and physical conditions who contract COVID-19. While the impacts of the current COVID-19 crisis are felt throughout the Commonwealth in a myriad of ways, there is no greater concern than access to life saving care, and the ability of our health care system to respond to the anticipated need for intensive care and ventilator access for thousands of residents.

People with disabilities are, and will be, at high risk of contracting COVID-19, particularly those who are in congregate residential programs, state-operated institutional settings, prisons and jails, and long term care facilities. We recognize and appreciate that the Commonwealth is already making efforts to protect these residents' safety and their ability to access medically necessary services.

At this moment, it is also critical that state officials take specific steps to ensure that life-saving care is not illegally withheld from disabled citizens, including aging adults with co-morbid conditions, due to discriminatory resource allocation or altered standards of care.

All state and private entities overseeing the delivery of life-saving medical interventions must make treatment decisions consistent with the non-discrimination requirements of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and Section 1557 of the Affordable Care Act. Yet around the country national and state advocacy groups are confronting outdated and discriminatory policies on emergency resource allocation in which

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individuals with specific disabilities or functional impairments can be denied access to, or subjected to the removal of, medically necessary ventilators. [1]

In response to such policies, the National Council on Disability (NCD)[2] and the Consortium for Citizens with Disabilities (CCD)[3] have proposed important principles for the delivery of care. In keeping with those national organizations, and consistent with our respective organizations' missions, we urge the Commonwealth to immediately adopt and disseminate mandatory statewide guidelines which clarify the following:

1) that the ADA and Section 504 require government decisions regarding the allocation of treatment/life-saving resources to be made based on individualized determinations, using current objective medical evidence, not generalized assumptions about a person's disability;
2) that the ADA and Section 504 prohibit treatment allocation decisions based on misguided assumptions that people with disabilities experience a lower quality of life, or that their lives are not worth living;
3) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person with a disability has a lower prospect of survival;
4) that the ADA and Section 504 prohibit treatment allocation decisions based on the perception that a person's disability will require the use of greater treatment resources; and
5) that a person is "qualified" for purposes of receiving COVID-19 treatment if he or she can benefit from the treatment (that is, can recover) and the treatment is not contraindicated.[4]

The Massachusetts Department of Public Health has draft documents dating back to 2007 that state, at a high level of generality, the importance of non-discrimination in treatment decisions made under altered standards of care.[5] However, these documents do not directly address the resolution of critical questions concerning how allocation of resources will occur at a time when demand exceeds system capacity. Nor do they provide specific guidance to private hospitals and ethics committees who will be on the front lines of thousands of individual treatment decisions. These guidelines simply direct that limited medical resources will be allocated in a way that maximizes the number of lives saved. This approach to maximization is

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[1] Office of Civil Rights complaints filed against the States of Washington and Alabama can be found at https://www.centerforpublicrep.org/news/cpr-and-partners-file-second-complaint-regarding-illegal-disability-discrimination-in-treatment-rationing-during-covid-19-pandemic/

[2] *See*, Letter of National Council to Roger Severino, Director, Office for Civil Rights, U.S. Department of Health & Human Services, March 18, 2020, available at https://ncd.gov/publications/2020/ncd-covid-19-letter-hhs-ocr

[3] CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

[4] *See*, Consortium of Citizens with Disabilities, letter to Secretaries of EOHHS and the Office of Civil Rights, March 20, 2020, available at http://www.c-c-d.org/fichiers/Letter-re-COVID-19-and-Disability-Discrimination-final.pdf

[5] *See*, 2007 draft version of Massachusetts Altered Standards of Care, available at http://www.cidrap.umn.edu/practice/altered-standards-care-guidelines

often informed by an assessment of "comparative ability to benefit" from treatment, which then leads to conscious or unconscious discrimination based on disability.[6]

Rather, what is needed is a set of mandatory principles like those listed above, prohibiting discrimination and requiring the application of individualized and objective medical standards that deny or remove care only when continued treatment would be futile. Without the creation of a statewide policy, and a meaningful appeal process, the exercise of medical discretion across the Commonwealth will be largely unchecked, unguided, and subject to wide variation. The unavoidable result will be highly subjective decision-making, needlessly placing even greater responsibility and stress on treating professionals.

Failure to act also presents the unacceptable risk that misplaced societal views about the relative quality or value of the lives of people with disabilities will result in their denial of life-saving treatment.

We are on the precipice of a statewide crisis in access to care, as the Governor has so aptly pointed out in recent press briefings. We applaud the strategic steps being taken to avert a crisis in managing both the rates of COVID-19 infection and the comprehensiveness of the Commonwealth's response. Massachusetts has an opportunity to be a national leader on these issues, by acting to establish equitable, democratic and nondiscriminatory standards of care before scarcity begins driving medical decisions across the Commonwealth.

We stand ready to assist in these efforts, and can quickly bring to bear a range of local and national resources and expertise, including emerging best practices, to support the Governor, the COVID-19 command center, and the Department of Public Health. At a minimum, we ask that you confirm your receipt of this letter and make clear how the Commonwealth intends to address the disability community's concerns regarding discriminatory rationing of care.

Thank you in advance for your consideration of this most important issue, and for your long–standing commitment to Massachusetts' citizens with disabilities.

Sincerely,

Cathy Costanzo, Executive Director
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Danna Mauch, President and CEO
Massachusetts Association for Mental Health

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[6] May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing, Samuel R. Bagenstos, University of Michigan Law School, pp. 8-10, March 24, 2020, available at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3559926. An article published this week in the New England Journal of Medicine applies this rationale even to removing the existing use of a ventilator from one person, to provide it to another, with the aim of "maximizing benefits." https://www.nejm.org/doi/full/10.1056/NEJMsb2005114?query=RP This reasoning could be used to justify the repossession of ventilators currently being used by persons with disabilities for conditions that began long before COVID-19, for example ALS patients, and evokes long-repudiated theories of eugenics.

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